

Reality Lessons in Traumatic Brain Injury

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Abstract

This article goes beyond the typical guidance on how to address the educational needs of students with traumatic brain injury (TBI). A survivor of TBI and his parent advocate describe real-life encounters in the education arena and offer ways to respond to the problems depicted in the situations. Their candor enhances educator awareness of the users' perspective. Ten topical incidents are provided, each followed by a summary of the lesson learned from the incident. Some of the issues and responses are controversial. All increase awareness of the realities faced by survivors of TBI and should spark discussions of alternative approaches for addressing the needs of students with TBI. Topics range from structuring a purposeful classroom environment to stimulating student creativity.

Keywords

traumatic brain injury, academic accommodations, academic disabilities, attitudes toward disabilities

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Introduction

Al is an African-American male, 32 years old, who experienced a traumatic brain injury (TBI) as the result of a motor vehicle accident at age of 16. Over the years following his accident, he completed high school and earned both an associate's degree and a bachelor's degree. Comatose following the injury, he spent more than a week in an intensive care unit at a major urban medical center. Eventually, he was transferred to a rehabilitative hospital where he spent months receiving a variety of therapies for both brain and spinal cord injuries. The brain injury was permanent; however, the spinal cord injury healed

to a stage where his physical restrictions were minimal, chiefly limitations on lifting. This article describes and analyzes several of Al's encounters with the education system after leaving hospitalbased rehabilitation. The purpose of this article is to facilitate efforts by educators to encourage the school success of students with TBI.

Lesson One: Prepare the Educators

Nearly a year passed after his accident before Al was able to return to his former high school. For several months following his discharge from the rehabilitation center, he was at home working on physical and social aspects of his recovery. Later, he received academic support in a non-traditional school setting. He was adamant that his goal was to return to his former high school although it was a private high school with no formal program for special needs students. Unfortunately, the return to the pre-injury high school was a disastrous experience. The faculty's preparation for Al's return appeared to have consisted of discussions concluding that Al was back and Al was different. Over the

course of the semester at the school, the advocate met with the school counselor to discuss concerns about Al's transition, but it was evident that Al no longer represented the school's core clientele and that he would continue to encounter frustration if he remained at the school.

Lesson Learned

Particularly at schools not focused on handling students with disabilities, there is limited or no understanding of TBI. Even at schools offering special needs services, TBI often falls through the cracks because it is misperceived as rare. According to a study by

> Mohr and Bullock (2005), many educators first learn about TBI when they are notified that they will receive a student with TBI in their class. Interestingly, the same study revealed that, lacking formalized training, the teachers utilize the Internet as their most popular informal source of information

on the subject. It is important that school briefings on disabilities include information on TBI and on strategies for working with these students. One convenient source of information is a resource guide on traumatic brain injury by Monfore (2005) that presents some of the terminology, organizations, web links, and books associated with TBI.

Post-injury, Al had individuals at each of the two traditional high schools he attended who were assigned informally to coordinate his re-entry process. Both were class counselors, whose primary focus by virtue of the large numbers of students served was not on special needs services. Clark (1996) indicates that a more formal procedure should be established, taking into consideration the fact that in educating the student with TBI, the case manager is the "most critical team member

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other than the classroom teacher." The assigned case manager should be knowledgeable about TBI or willing to learn about it. Clark also provides a "Suggested School Reintegration Checklist" that can be used by the case manager and other members of the school team to facilitate the transition of the student with TBI into the school setting. The list covers actions to be taken immediately following the injury through the first weeks at school.

Lesson Two: Prepare the Student Peers

Although Al's classmates visited him during his hospital recovery, the group of peers that gave him the strongest support was from the youth group at his church. Al's accident had occurred while he was on the way home from school with a classmate. For some

of his school peers, seeing a classmate in Al's fragile condition reminded them of their own vulnerabilities, raising their personal anxieties. When Al returned to the high school the following fall, his class had moved on, and he was now with a totally different set of students. There was teasing; there was distraction; and there was comparison of the new Al with the old

Al. Al himself persisted in the belief that he could return to the old school and regain his pre-accident status. This was clearly not to be.

The fact sheet on traumatic brain injury produced by the National Information Center for Children and Youth with Disabilities (1999) notes that return to school is often accompanied by many emotional and social changes in the student with TBI. At the same time, "The child's family, friends, and teachers also recall what the child was like before the injury. These other people in the child's

life may have trouble changing or adjusting their expectations of the child." Al and his advocate seriously considered whether the pre-injury school environment was preferable to a fresh start and eventually ended up with the latter. No matter whether the decision is to remain at the pre-injury school or to change to another school setting, student peers need to be prepared.

Lesson Learned

Klotz (2004) recommends that teachers aid student peers in understanding the effects of Traumatic Brain Injury on their classmate and encourage their empathy. Recently, because of the prevalence of TBI among combat injuries in Iraq, more media attention has been directed to the disability, which may increase students' awareness of

TBI. Bob Woodruff, the former

ABC news anchor who suffered a TBI while reporting in Iraq, has been a charismatic spokesperson for TBI. He has been careful to feature in his reports the variability of the effects of TBI. Klotz (2004) also encourages the use of peer partners to serve as lunch buddies or study mates. She condemns bullying, particularly name-calling, teasing,

and intimidation as especially hurtful to the injured student.

Clark (1996) suggests that "in-class meetings be arranged to provide information to peers about the student's condition and to prepare them for his or her return." She expressed hope that this would reduce the odds of the student with TBI being abandoned because of his or her new "difference." As a cautionary note, teachers should respect the limits set by the student with TBI on how much information to share with classmates.

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Lesson Three: Move on From No

Al and his advocate explored several special needs schools for his immediate postinjury academic transition. One school was particularly well-located, attractive, and spacious. The school literature indicated that it selected students interested in completing their education who needed a prescriptive educational program. This school seemed to fit precisely Al's needs. However, after the visit by Al and his advocate, the admissions director denied Al's enrollment. Her rationale

was that the school once had enrolled a TBI student and that he roamed around the building lost. She claimed that the school was afraid that Al also would get lost. Although the advocate explained that there was considerable variability among TBI survivors, the school official was firm in her

decision that Al was not a suitable candidate for enrollment.

It was obvious that the school administration was uncomfortable working with students with TBI and unwilling even to consider accommodations. The school also made it very clear that it accepted no government funds, limiting its obligations for open admissions. At this point, Al and his advocate both agreed that it would not be helpful for him to be exposed to the consequences of being an unwanted student. In this case, the upfront rejection, while immediately hurtful, spared the student potential frustration in the future.

Lesson Learned

A school, even one cited for excellence, is only as good as its response to the needs of individual students. Sociologist Robert Merton has described the *self-fulfilling prophecy* as a belief or expectation, whether correct or not, that, in being made, actually causes itself to become true. Tauber (1998) confirms in his studies that "Teachers, more often than not, get from students what they expect from them!" A school setting that is openly negative to the presence of students with TBI can only add to the demoralization the students are already experiencing as a result of the injury. Students with TBI deserve a warm and supportive educational team that focuses on the students' real assets rather than on their potential deficits.

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Lesson Four: Structure a Purposeful Environment

In several instances, Al's post-injury classroom environments were recipes for failure in terms of the needs of a student with TBI. His initial schooling involved one on one

instruction. The teacher positioned Al and himself just inside the classroom entry with the door open during the instruction. Needless to say, Al was distracted from his studies every time someone passed in the corridor. Later, he attended classes with peers in a traditional classroom. Distractibility was again a concern. Individual students recognized how easily Al could be distracted and would often whisper his name to him in class for the amusement of his confused response.

It was a teacher who committed the ultimate folly. During a make-up test, the teacher repeatedly distracted Al and roused his anxiety by waving Al's lunch and threatening to eat it. In each case, teachers and students were treading new ground in their encounters with students with TBI. The activities appeared to be driven more by ignorance and mischief-making, rather than personal malice. The teachers were immature and un-



trained in special services, and the students had not been prepped on how to be supportive of a special needs peer.

Lesson Learned

Among the cognitive impairments that students with TBI may experience are attention deficits, memory failures, lack of organization, impaired problem-solving, and slowed writing and information processing speeds. Bowen (2005) presents a very useful table of external aids and teaching/learning strategies that help compensate for these weaknesses. Hibbard, Gordon, Martin, Raskin, and Brown

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(2001) also offer examples of classroom accommodations addressing the cognitive challenges of the student with TBI. Among the actions that could have been taken to limit Al's distractibility would be positioning Al's seating near the teacher (not, however, in a doorway), providing him with a study carrel, and removing from the carrel extraneous materials not being used in the class.

Bowen also suggested the use of earplugs to reduce external noise while the student works on assignments.

Lesson Five: Partner with the Advocate

Prior to his accident, Al had been a hurdler in high school track and field events. He had been fairly good at the hurdles, but since the accident, his skills had been affected by natural changes in his physique as a result of growing up, as well as residual effects of his injuries. Al, however, was in denial concerning these personal changes and envisioned himself as he was before the accident. The school personnel, on the other hand, were

reluctant to deny him the opportunity to participate in an activity open to all students. Initially, Al, his advocate, and the school agreed that Al could participate in hurdling, but would be monitored closely. It soon became clear that Al was knocking down more hurdles than he was clearing, often stumbling and picking up bruises and scratches in the process.

While Al desired to continue his sport, school personnel and the advocate reluctantly decided to persuade him to terminate his participation. There were concerns that Al might be headed to more serious injury and that the

> school was certainly risking liability. Al was helped by his coach and his advocate to understand why it was in his best interest to cease this activity. In lieu of sports activity, Al turned to the school yearbook and newspaper as his extracurricular outlets.

Al's persistence in defining himself as a hurdler represented both cognitive im-

pairment and physical impairment associated with TBI. Bowen (2005) reports that "Physical functioning can also be markedly impaired following severe TBI." She mentions loss of function in all or some extremities, spasticity, decreased motor speed, and poor coordination in fine or gross motor movements as potential problems. Al's cognitive issue fell into the category of lack of awareness of impairments and needs, while the physical difficulties focused on his weakened motor skills.

Although Gardner (2001) cautions the student with TBI that "you are responsible for being your own advocate," sometimes the





student is unwilling or unable to address a situation that brings hazard into the student's life. Rather than accept at face value what the student with TBI reports about his or her ability to perform the task at hand, school personnel and the advocate for the student must monitor performance carefully and intervene when necessary to protect the student. The student should receive a clear explanation of why the intervention is necessary, and alternative options should be developed through dialogue involving student, school personnel, and advocate.

Lesson Six: Recognize New Student in Old Package

Al enrolled at the high school from which he graduated in the middle of his junior year. The school's academic team was wary about receiving a school transfer at such a critical point and accepted Al only after he signed a contract acknowledging probationary status with specific goals to be met. The teachers were highly supportive, but uncom-

promising in their demand that Al meet their academic standards. Pre-injury, Al had taken a non-credit college-level chemistry course in a program for gifted students and had performed very well. Post-injury, TBI made memorizing and computing formulas difficult. Since successful completion of

the chemistry course was a graduation requirement, there was considerable desperation on the part of Al, the teacher, the senior counselor, and the advocate. Al's self-confidence plummeted. Fortunately, the school counselor was able to recommend a tutor known for being able to teach chemistry to students in the most abysmal situations. The intensive tutoring worked, and when Al finally passed the

exam, tears flowed from many sources.

Lessons Learned

Al's struggle with chemistry was not surprising. Gardner (2001) points out that "Academic tasks, such as the precise sequencing of steps required in a chemistry experiment or applying theoretical math formulas to solve word problems, can prove very challenging. The student may require special accommodations..." Gardner also notes that "A student's learning habits prior to injury can either positively or negatively influence future learning." Al fell into the category of very bright students who coasted through classes pre-TBI. He was frustrated that since his injury, he had to work considerably harder. The relaxed, unstructured effort that previously generated passing grades no longer worked. Effort now had to be intensified and organized. Those study skills that previously seemed unimportant for classroom success became critical.

Lesson Seven: Stimulate Creativity

Much attention after the accident was directed at facilitating Al's academic achievement. On the other hand, engaging in creative activities can add much joy to life and relieve the pain of the transition to a new life that TBI of-

ten requires. During the summer following Al's injury, he and his advocate discovered that the Ensemble Theatre's Young Performers Program offered young people aged 7 through 17 arts education, creative dramatics, and performance opportunities. Beyond teaching the arts, the Ensemble's director indicated that the program also provided "a place of discovery

Sometimes a student is unwilling or unable to address a situation that brings hazard into the student's life.



where young people build confidence, friendships, and discover the art in themselves." After a discussion of Al's special needs, it was determined that Al could be accommodated. Proudly, Al participated in a live theatrical performance at the end of the summer session in which his lines were few because of his short term memory issues, but his humor and physicality favorably complimented his role.

Even before his accident Al had dabbled in poetry. After the accident, when he was feeling down, he was encouraged to express his ideas through poetry. Tools like a rhyming book kept him busy looking for the right word matches, enhancing his vocabu-

lary. Al's poetry often spoke of lost love, since he was dating his first official girl when the accident occurred. Although, one can explain over and over that at 16 one is just discovering love and most relationships formed at 16 are not permanent, this is not what the young person wants to

hear. Al decided to channel his hurt into his poems, wearing a tie with an arrow-pierced heart that he called his poet tie.

Lesson Learned

Sally Bailey (1993) points out in Wings to Fly a host of skills that the arts can develop, including listening, eye contact, body awareness, physical coordination, facial and verbal expressiveness, focus and concentration, as well as others. TBI survivors can also engage in problem-solving, building selfesteem, and developing social interaction skills through creative activities. Moreover, the arts can also serve as a means of channeling frustration in a positive direction. The National Arts and Disability Center provides a variety of resources and a library online linking the arts and people with disabilities

(2007). The center's electronic help desk can assist educators with specific questions. The special education team is urged to work with school drama programs and writing clubs to include special needs students, providing insight into how to incorporate the students' unique talents.

Lesson Eight: Encourage Activism

Like most adolescents, Al desired desperately to fit in with his peers. He studiously avoided any group that might identify him as having a disability. For example, the rehabilitation center offered monthly group meetings for former clients, but Al refused to

> attend them. When Al reached the community college level, the ADA Counselor gently prodded him to consider joining the Student Organization for Disability Awareness (SODA) on campus. This organization informs students about disability issues, self-empowerment, promotes

offers career coaching, supports networking, and encourages participation in both on and off campus activities related to disabilities.

Al discovered that membership in SODA provided avenues for meeting not only students with disabilities, but also students from a variety of interest groups. His activities in SODA led him to broader activism on campus, learning how to work with others to achieve his goals, a skill with lifelong implications. He was elected Student Government President during his last semester at the community college and received recognition at Awards Day from the College's President.

Lesson Learned

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The Student Organization for Disability Awareness (SODA) is just one of several organizations that serve students with dis-



abilities on college campuses. Evanston Township High School in Illinois, for example, offers the Disability Awareness Club. Schools or colleges that currently don't offer organizational presence to students with disabilities should consider the benefits-selfempowerment and faculty/student support. The National Council for Support of Disability Issues (NCSD) offers "A Guide to Organizing a Disabled Student Services Club" on its web site. It is most important to have an assigned adviser that is familiar with the needs of student with disabilities and can pursue satisfactory responses to them. For example, impulsivity often poses a difficulty for students with TBI. The adviser should monitor student activities and ensure that students

needing help with this issue are provided appropriate management tools to achieve successful organizational participation.

channel his hurt into poems.

Al decided to

serving a student with special needs, but rather on meeting the coach/principal's dream of a winning basketball team. He did not enroll.

When Al progressed to college, student services personnel were informed that he had a disability, but often failed to grasp why he needed residential accommodations for the handicapped (single room accommodations). Al would request a single room and the automatic response would be that "Yes, we can provide you a room with a ramp." No matter that Al gave no indication that he needed a ramp. Al needed the single accommodations to avoid distraction and establish a better sleep environment, common concerns for individuals with TBI.

> Ironically, on the one occasion when a student with a temporary mobility difficulty (sprained ankle) did surface needing a room with a ramp, Al was summarily bumped to another residence hall to share a room with a football player.

Lesson Learned

Al's experiences with the "room with a ramp" are explained by the fact that, according to Mayfield and Homack (2005), "Children who have obvious physical deficits associated with their TBI are most easily understood, and accommodations are readily provided." Cave (2004) points out that "The long-term results of brain injuries in children are poorly understood and often undervalued because the injury's impact may not be immediately evident." With a closed head injury, there might not even be a scar as a sign. Mayfield and Homack facetiously suggest that "If the child had a cast on his or her head, that would serve as a reminder that the child will require modification, academically and behaviorally, for some time."

Lesson Nine: Beware of Invisibility

TBI is often described as an invisible disability because it may not be immediately clear that a survivor has a disability. Al has encountered this confused response on numerous occasions. One amusing instance occurred when he and his advocate were visiting a high school shortly after his release from rehabilitation. The coach/principal at the school was facing a major basketball game the day following the meeting. He was, therefore, delighted by Al's 6'2" height. The first words he blurted out were "Can you shoot a basket?" and "Would you be able play at tomorrow night's big game?" Al's status as a student with TBI was overlooked completely. Although Al received immediate acceptance to this school, Al and his advocate realized that the school's focus seemed not to be on



It is important to provide educators with any documents that help clarify the student's situation. It is also vital for the advocate to communicate needs that the students may fail to share. When the student reaches 18, it will be necessary to have a letter prepared with the student's approval that permits the advocate to discuss the student's disability and attendant needs, since confidentiality regulations might otherwise prevent discussion with any one other than the student.

Lesson Ten: Facilitate Transition to Postsecondary Education

Al completed the college prep curriculum at a private high school. His transitional career advisement from the school was the same as the guidance offered to all graduates. Unfortunately, it included no information on

accommodative higher education environments. Al and his explored advocate postsecondary opportunities independently, utilizing Peterson's Colleges with Programs for Students with Learning Disabilities. After reviewing options, a private out-of-state col-

lege was selected where Al spent his first year of college. The following year, he returned home to a local community college after a family decision to conserve his financial resources for later support, if needed.

Al targeted Physical Therapy and Radio/TV Broadcasting as majors. Like many college students, his selection of majors was somewhat fickle. Physical therapy, for example, was probably selected because of Al's strong identification with his therapist during rehab. The choice did not take into consideration the physical requirements for the profession. Radio/TV broadcasting followed up on activities that interested Al in high school, but

he did not consider the stressful competition and rapid decision-making associated with broadcast work. When Al was job-hunting after college graduation, he visited a vocational counselor at the Texas Department of Assistive and Rehabilitative Services (DARS). This counselor prescribed career assessment services, and through this testing and counseling he discovered where his career skill assets were. He modified his career goal to customer services, where he is currently employed.

Lesson Learned

Shortcomings

remain in

preparing teachers

to work with

students with TBI.

A key element in providing career assistance to the students with TBI is helping them to recognize that their pre-TBI career goals may need adjustment to fit their post-TBI skills and abilities. As D'Amato and

> Rothlisberg (1996) point out, that incorporated assistive and

rehabilitative services from the state might have guided him more efficiently. Savage (2005) provides some aid in this area to family and educators through family and professional staff checklists that address transitional needs for students with disabilities aged 14 to 21. It should be noted that public schools are required by law to provide transitional services. Savage also offers a planning list for education after high school that is a helpful tool applicable in both private and public high school settings.

"students...suddenly find themselves at a different functional level than they anticipated before injury." While Al eventually navigated the transition from high school to college to workforce, a more coordinated plan



Conclusion

Bullock, Gable, and Mohr (2005) indicate that "the largest number of students with TBI were served in more restrictive educational environments, ranging from outside the regular class to separate day and residential facilities to homes or hospitals." Most of Al's post-rehab education occurred in inclusive settings where there was limited familiarity with TBI. Over the course of the nine years from the time of his accident to his college graduation, he dealt with a variety of situations that gave him and his family member advocate unique insights into TBI and the responses of the education community to it.

The ten lessons presented range from teacher preparation to peer relationships. Concerns about rejection and invisibility are explored. There is also emphasis on enabling student creativity and activism. As Keyser-Marcus, Briel, Sherron-Targett, Yasuda, Johnson, and Wehman (2002) point out, "The individual consequences of TBI vary greatly and depend on the student's pre-injury level of functioning, injury severity, location of injury, and recovery time post-injury." Al's post-injury experiences cannot be generalized to every student with TBI. However, there are many elements that are shared by members of the TBI community.

Bullock, Gable, and Mohr (2005) report that "There has been a slow, but steady, growth of services to students identified with a TBI in the nation's schools." This suggests that some of Al's experiences as a student with TBI won't be repeated with more recent students with TBI. The topical issues in this case study are still relevant, however. Shortcomings remain in preparing teachers to work with students with TBI, particularly those in general education settings with limited special needs services. Many students with TBI still await the broad repertoire of skills that will

help them enjoy a life, not just survive. An informed education community will have significant impact on lifting the veil of invisibility from this injury.

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